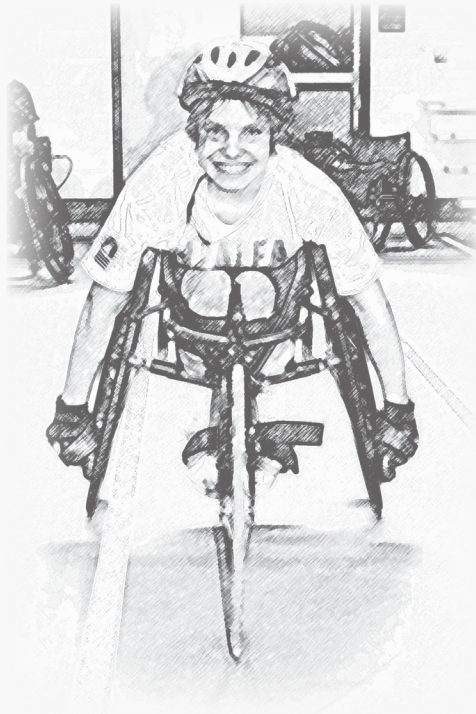


Alabama Chartbook

of

2009/10 Needs Assessment Findings
for Children and Youth with Special Health Care Needs
and Their Families



Statewide and by Children's Rehabilitation Service districts

Children's Rehabilitation Service (CRS), a division of the Alabama Department of Rehabilitation Services, is a statewide organization of skilled professionals providing quality medical, rehabilitative, coordination, and support services for children with special health care needs and their families. Each of Alabama's 67 counties is served through a network of 15 community-based offices. This network provides services such as specialty evaluations, care coordination, information and referral, family education, and family and youth programs. Any child or adolescent younger than 21 years of age who is a resident of Alabama and has a special health care need is eligible for CRS.

In Alabama, the Title V Maternal and Child Health Program is administered by the Alabama Department of Public Health. This agency contracts with CRS to administer services to children and youth with special health care needs (CYSHCN), making CRS Alabama's Title V Children with Special Health Care Needs (CSHCN) Program. Given this relationship, CRS performs the CYSHCN portion of the federally-required five-year maternal and child health needs assessment for Alabama. For 2009-10, CRS partnered with Family Voices of Alabama (FVA) and the School of Public Health at the University of Alabama at Birmingham (UAB) to assist with the process.

Information in this document has been edited from the full submission to the Maternal and Child Health Bureau. The material presented highlights findings specific to CYSHCN. The full submission is available upon request through the Alabama Department of Public Health and will be available on the Maternal and Child Health Bureau website (<https://perfddata.hrsa.gov/MCHB/TVISReports/default.aspx>) mid-fall of 2010. Full statewide reports for CYSHCN are available on the ADRS/CRS website at www.rehab.alabama.gov/crs.

The following pages detail needs assessment findings related to CYSHCN and their families for the state as a whole and for individual CRS districts. These districts cover selected counties as follows:

District 1, Huntsville

Colbert, Franklin, Jackson, Lauderdale, Lawrence, Limestone, Madison, Marion, Marshall, Morgan, Winston

District 2/8, Homewood/Birmingham

Cullman, Jefferson, Shelby, Walker

District 3, Anniston

Blount, Calhoun, Cherokee, Clay, Cleburne, DeKalb, Etowah, St. Clair, Talladega

District 4, Tuscaloosa

Bibb, Dallas, Fayette, Greene, Hale, Lamar, Marengo, Perry, Pickens, Sumter, Tuscaloosa, Wilcox

District 5, Montgomery

Autauga, Bullock, Chambers, Chilton, Coosa, Elmore, Lee, Lowndes, Macon, Montgomery, Pike, Randolph, Russell, Tallapoosa

District 6, Dothan

Barbour, Butler, Coffee, Conecuh, Covington, Crenshaw, Dale, Geneva, Henry, Houston

District 7, Mobile

Baldwin, Choctaw, Clarke, Escambia, Mobile, Monroe, Washington

CRS Statewide CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 187,263¹

of Rural counties: 55 (82%)²

of Urban counties: 12 (18%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for State: 3.4

(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
(based on key informant interviews)

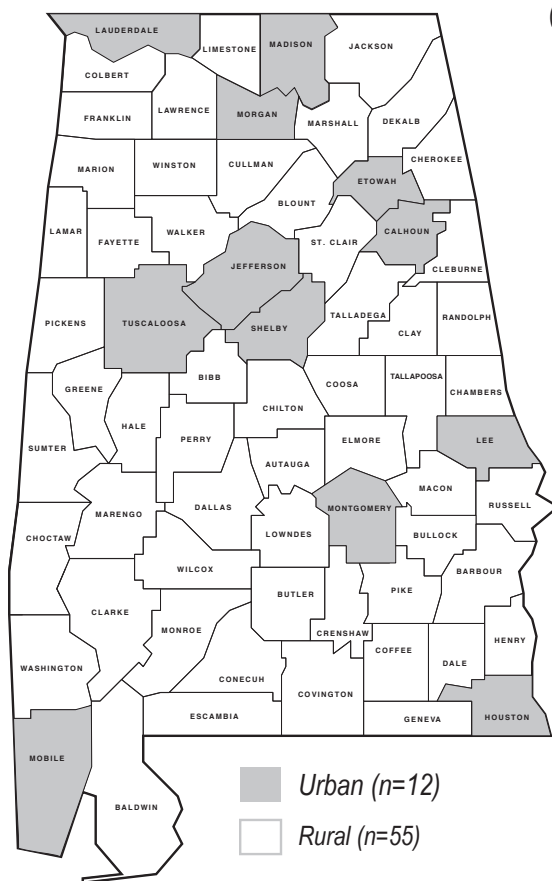
State at-a-glance

Mean % receiving SSI under age 18 ³	2.6
Mean % under age 18 living in poverty ⁴	27.4
Median income (\$) ⁵	35,558
Mean % under age 21 eligible for Medicaid ⁶	43.3
Mean % over age 25 with HS or greater education ⁷	69.6
Mean % over age 25 with BS degree or higher ⁷	13.5

Greatest service needs for CYSHCN and their families

Key informant interviews

1. Transportation
2. Respite care
3. Therapies (PT, OT, SP, nutrition)



Information needs identified by families

Family Survey; n=1,103

1. My child's condition or disability
2. Recreational activities
3. Successful persons living with condition/disability
4. Healthy behaviors (exercise, eating well, etc.)
5. Jobs/careers

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=1,103)
1. Transportation	1. Insurance didn't cover services
2. Families unsure how to use system	2. Did not know where to go/who to see
3. Lack of child care	3. Missed school days
4. Lack of information on resources and health needs	4. Transportation
5. Insurance does not adequately cover needed services	5. Can't afford co-pays and deductibles
6. Lack of health insurance	6. Services too expensive
7. Inadequate transition	7. Waiting list for services too long
8. Cultural/language barriers	8. Providers not available
9. Lack of facilities with convenient locations	9. Work conflict – Unable to take time off work
10. Providers not available	10. Work conflict – Can't afford to lose pay
11. Lack of facilities with convenient hours	11. Hours/location of providers not convenient
12. Costs of services too high	12. Lack of child care
13. State policy or administrative barriers	13. State policy or administrative barriers
	14. No insurance
	15. Language/cultural barriers

CRS Statewide CYSHCN Profile, 2009-2010 (continued)

Service availability, burden rating, and non-receipt of needed services

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)	Family Indicated Need for Service (%)***	Family Indicated Need for Service, But Did Not Receive (%)***
HEALTH SERVICES				
Dental	66 (99)	1.8	57.0	9.2
Developmental screening	66 (99)	2.0	35.0	9.6
Emergency care	66 (99)	1.7	27.9	2.0
Hearing/hearing aids	63 (94)	1.7	23.9	7.8
Mental health/behavioral	65 (97)	1.3	27.0	16.3
Nutrition	67 (100)	1.7	26.4	12.4
Occupational therapy	64 (96)	1.5	38.3	14.6
Physical therapy	67 (100)	1.6	37.7	8.2
Primary care	67 (100)	2.2	61.9	2.4
Special equipment or braces	61 (91)	1.5	35.4	8.4
Specialty care	65 (97)	1.5	43.2	3.9
Speech therapy	66 (99)	1.5	39.3	12.8
Vision/eyeglasses	66 (99)	1.8	43.2	6.9
COMMUNITY-BASED SERVICES				
Care coordination	66 (99)	1.9	16.8	18.9
Child care facilities/day care	64 (96)	1.6	19.0	32.0
Early Intervention	67 (100)	2.2	17.2	6.5
Education services	67 (100)	2.1	46.2	9.3
Family support	63 (94)	1.4	22.7	32.5
Planning for transition to adulthood	63 (94)	1.3	13.6	34.5
Recreation opportunities	63 (94)	1.3	22.9	35.1
Respite care	57 (85)	1.1	17.9	25.0
Summer/after-school care	58 (87)	1.4	20.2	42.1
Transportation assistance	58 (87)	1.2	20.9	23.2

*County provider survey, **Key informant interviews, ***Family Survey

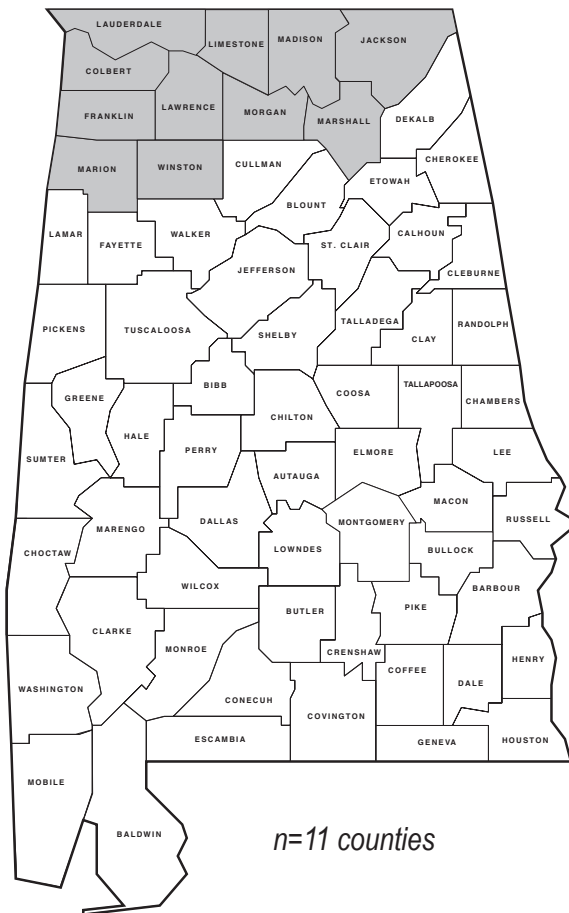
CRS District 1, Huntsville CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 37,616¹
Rural counties: 8 (73%)²
of Urban counties: 3 (27%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for District 1: 3.2

(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
(based on key informant interviews)



District at-a-glance

Mean % receiving SSI under age 18 ³	1.8
Mean % under age 18 living in poverty ⁴	23.9
Median income (\$) ⁵	37,530
Mean % under age 21 eligible for Medicaid ⁶	38.5
Mean % over age 25 with HS or greater education ⁷	70.5
Mean % over age 25 with BS degree or higher ⁷	14.5

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=150)
1. Transportation	1. Insurance didn't cover services
2. Families unsure how to use system	2. Can't afford co-pays and deductibles
3. Lack of child care	3. Services too expensive
4. Cultural/Language barriers	4. Providers not available (tie)
5. Insurance does not adequately cover needed services	Missed school days (tie)
6. Lack of health insurance	6. Lack of child care
7. Costs of services too high (tie)	7. Did not know where to go/who to see (tie)
Lack of information on resources/health needs (tie)	Work conflict – Unable to take time off work (tie)
9. Lack of facilities with convenient locations	9. Work conflict – Can't afford to lose pay (tie)
10. Inadequate transition	Hours/location of providers not convenient (tie)
11. Providers not available	Waiting list for services too long (tie)
12. Lack of facilities with convenient hours	12. Transportation
13. State policy or administrative barriers	13. State policy or administrative barriers
	14. No insurance
	15. Language/Cultural barriers

CRS District 1 CYSHCN Profile, 2009-2010 (continued)

Service availability and burden ratings

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)
HEALTH SERVICES		
Dental	11 (100)	1.5
Developmental screening	11 (100)	1.9
Emergency care	11 (100)	1.6
Hearing/hearing aids	11 (100)	1.5
Mental health/behavioral	11 (100)	1.2
Nutrition	11 (100)	1.5
Occupational therapy	10 (91)	1.5
Physical therapy	11 (100)	1.7
Primary care	11 (100)	2.3
Special equipment or braces	10 (91)	1.4
Specialty care	11 (100)	1.6
Speech therapy	11 (100)	1.5
Vision/eyeglasses	11 (100)	1.7
COMMUNITY-BASED SERVICES		
Care coordination	11 (100)	1.7
Child care facilities/day care	10 (91)	1.5
Early Intervention	11 (100)	2.3
Education services	11 (100)	1.9
Family support	10 (91)	1.5
Planning for transition to adulthood	11 (100)	1.5
Recreation opportunities	10 (91)	1.5
Respite care	9 (82)	1.3
Summer/after-school care	9 (82)	1.5
Transportation assistance	8 (73)	1.3

*County provider survey, **Key informant interviews

Information needs identified by families

Family Survey; n=150

1. Recreational activities
2. Successful persons living with condition/disability (tie)
Healthy behaviors (exercise, eating well, etc.) (tie)
My child's condition or disability (tie)
3. Jobs/careers

Greatest service needs for CYSHCN and their families

Key informant interviews (# of counties indicating need)

- | | |
|-------------------|-----------|
| 1. Transportation | 11 (100%) |
| 2. Respite care | 9 (82%) |
| 3. Child care | 7 (64%) |

CRS District 2/8, Homewood/Birmingham

CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 41,556¹
 # of Rural counties: 2 (50%)²
 # of Urban counties: 2 (50%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for District 2: 3.0

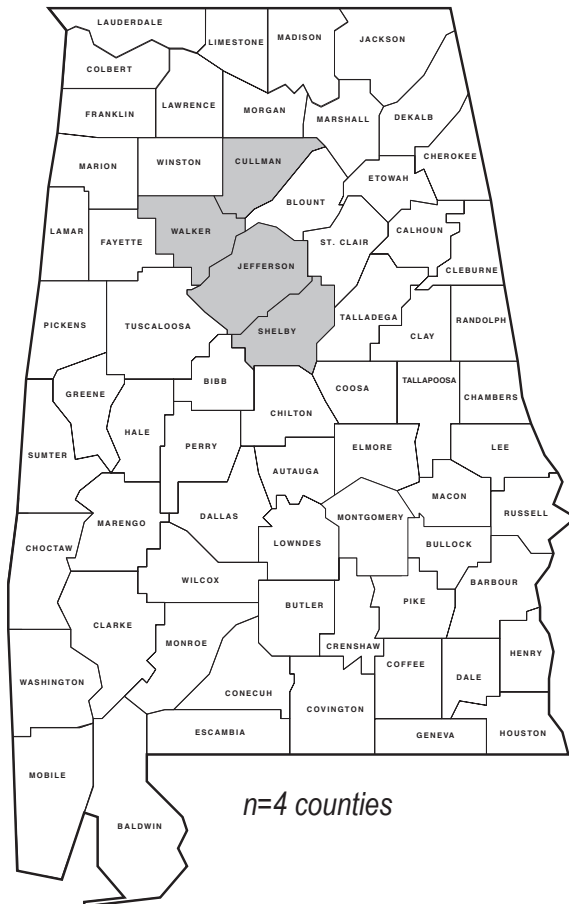
(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
 (based on key informant interviews)

District at-a-glance

Mean % receiving SSI under age 18 ³	2.1
Mean % under age 18 living in poverty ⁴	18.6
Median income (\$) ⁵	42,051
Mean % under age 21 eligible for Medicaid ⁶	31.6
Mean % over age 25 with HS or greater education ⁷	76.3
Mean % over age 25 with BS degree or higher ⁷	20.6

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=178)
1. Lack of health insurance (tie)	1. Services too expensive (tie)
Insurance does not adequately cover needed services (tie)	Did not know where to go/who to see (tie)
Transportation (tie)	3. Insurance didn't cover services
Families unsure how to use system (tie)	4. Can't afford co-pays and deductibles
Lack of child care (tie)	5. Missed school days
6. Cultural/language barriers (tie)	6. Providers not available
Inadequate transition (tie)	7. Work conflict – Unable to take time off work
8. Lack of facilities with convenient hours (tie)	8. Transportation
State policy or administrative barriers (tie)	9. Hours/location of providers not convenient (tie)
10. Lack of information on resources/health needs	Waiting list for services too long (tie)
11. Cost of services too high	Lack of child care (tie)
12. Lack of facilities with convenient locations	12. Work conflict – Can't afford to lose pay (tie)
13. Providers not available	State policy or administrative barriers (tie)
	14. No insurance
	15. Language/Cultural barriers



CRS District 2/8 CYSHCN Profile, 2009-2010 (continued)

Service availability and burden ratings

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)
HEALTH SERVICES		
Dental	4 (100)	2.0
Developmental screening	4 (100)	2.0
Emergency care	4 (100)	2.0
Hearing/hearing aids	4 (100)	2.0
Mental health/behavioral	4 (100)	1.0
Nutrition	4 (100)	1.7
Occupational therapy	4 (100)	2.0
Physical therapy	4 (100)	2.0
Primary care	4 (100)	2.0
Special equipment or braces	4 (100)	1.7
Specialty care	4 (100)	1.5
Speech therapy	4 (100)	1.7
Vision/eyeglasses	4 (100)	2.0
COMMUNITY-BASED SERVICES		
Care coordination	4 (100)	2.0
Child care facilities/day care	4 (100)	1.2
Early Intervention	4 (100)	2.0
Education services	4 (100)	2.0
Family support	4 (100)	2.0
Planning for transition to adulthood	4 (100)	1.0
Recreation opportunities	4 (100)	1.5
Respite care	4 (100)	1.0
Summer/after-school care	4 (100)	1.0
Transportation assistance	4 (100)	1.5

*County provider survey, **Key informant interviews

Information needs identified by families

Family Survey; n=178

1. Recreational activities
2. My child's condition or disability
3. Healthy behaviors (exercise, eating well, etc.)
4. Jobs/careers
5. Successful persons living with condition/disability

Greatest service needs for CYSHCN and their families

Key informant interviews (# of counties indicating need)

1. Transportation 3 (75%)
2. Respite care (tie) 2 (50%)
 - Summer/after-school care (tie)
 - Child care (tie)
3. Transition (tie) 1 (25%)
 - Cultural/language barriers (tie)
 - Support services (tie)

CRS District 3, Anniston

CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 22,568¹
 # of Rural counties: 7 (78%)²
 # of Urban counties: 2 (22%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for District 3: 3.4

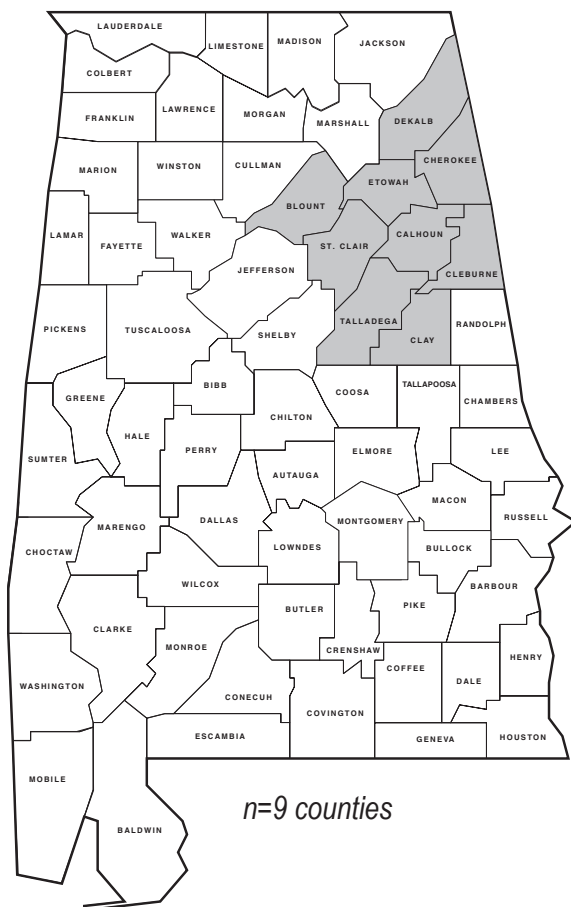
(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
 (based on key informant interviews)

District at-a-glance

Mean % receiving SSI under age 18 ³	2.0
Mean % under age 18 living in poverty ⁴	23.3
Median income (\$) ⁵	37,478
Mean % under age 21 eligible for Medicaid ⁶	42.5
Mean % over age 25 with HS or greater education ⁷	68.4
Mean % over age 25 with BS degree or higher ⁷	10.6

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=235)
1. Transportation	1. Did not know where to go/who to see
2. Families unsure how to use system	2. Missed school days
3. Lack of facilities with convenient locations	3. Insurance didn't cover services (tie)
4. Insurance does not adequately cover needed services (tie)	Transportation (tie)
Cultural/language barriers (tie)	5. Waiting list for services too long
6. Lack of health insurance (tie)	6. Hours/location of providers not convenient (tie)
Cost of services too high (tie)	Services too expensive (tie)
8. Providers not available (tie)	Can't afford co-pays and deductibles (tie)
Lack of facilities with convenient hours (tie)	9. Lack of child care
10. Lack of child care	10. Work conflict – Unable to take time off work
11. Lack of information on resources/health needs	11. Providers not available (tie)
12. Inadequate transition	Work conflict – Can't afford to lose pay (tie)
13. State policy or administrative barriers	13. State policy or administrative barriers
	14. No insurance
	15. Language/Cultural barriers



n=9 counties

CRS District 3 CYSHCN Profile, 2009-2010 (continued)

Service availability and burden ratings

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)
HEALTH SERVICES		
Dental	9 (100)	1.9
Developmental screening	9 (100)	1.8
Emergency care	9 (100)	1.7
Hearing/hearing aids	9 (100)	1.7
Mental health/behavioral	9 (100)	1.6
Nutrition	9 (100)	1.8
Occupational therapy	9 (100)	1.7
Physical therapy	9 (100)	2.0
Primary care	9 (100)	2.1
Special equipment or braces	9 (100)	1.2
Specialty care	9 (100)	1.2
Speech therapy	9 (100)	1.6
Vision/eyeglasses	9 (100)	1.6
COMMUNITY-BASED SERVICES		
Care coordination	9 (100)	1.8
Child care facilities/day care	9 (100)	1.7
Early Intervention	9 (100)	2.2
Education services	9 (100)	2.3
Family support	9 (100)	1.2
Planning for transition to adulthood	9 (100)	1.3
Recreation opportunities	9 (100)	1.4
Respite care	7 (78)	1.0
Summer/after-school care	7 (78)	1.4
Transportation assistance	8 (89)	1.1

*County provider survey, **Key informant interviews

Information needs identified by families

Family Survey; n=235

1. My child's condition or disability
2. Recreational activities
3. Successful persons living with condition/disability
4. Healthy behaviors (exercise, eating well, etc.)
5. How my child can take care of medical needs independently (tie)
Jobs/careers (tie)

Greatest service needs for CYSHCN and their families

Key informant interviews (# of counties indicating need)

- | | |
|---------------------------|---------|
| 1. Transportation | 8 (89%) |
| 2. Respite care | 5 (56%) |
| 3. Therapies (OT, PT, SP) | 4 (44%) |

CRS District 4, Tuscaloosa CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 15,517¹
of Rural counties: 11 (92%)²
of Urban counties: 1 (8%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for District 4: 3.7

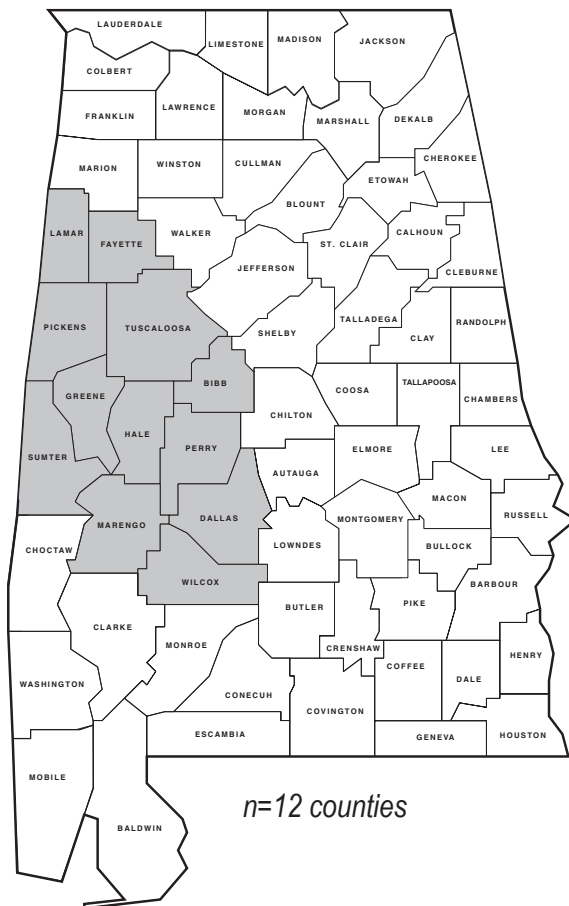
(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
(based on key informant interviews)

District at-a-glance

Mean % receiving SSI under age 18 ³	4.1
Mean % under age 18 living in poverty ⁴	34.3
Median income (\$) ⁵	31,489
Mean % under age 21 eligible for Medicaid ⁶	49.7
Mean % over age 25 with HS or greater education ⁷	66.8
Mean % over age 25 with BS degree or higher ⁷	11.3

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=161)
1. Transportation	1. Missed school days
2. Inadequate transition	2. Transportation
3. Lack of information on resources/health needs	3. Insurance didn't cover services
4. Families unsure how to use system	4. Waiting list for services too long
5. Lack of facilities with convenient locations	5. Can't afford co-pays and deductibles (tie)
6. Cost of services too high	Services too expensive (tie)
7. Lack of child care	Providers not available (tie)
8. Providers not available	Work conflict – Unable to take time off work (tie)
9. Lack of facilities with convenient hours	Work conflict – Can't afford to lose pay (tie)
10. Lack of health insurance (tie)	10. Did not know where to go/who to see
Insurance does not adequately cover needed services (tie)	11. No insurance
12. State policy or administrative barriers	12. Hours/location of providers not convenient (tie)
13. Cultural/language barriers	Lack of child care (tie)
	14. State policy or administrative barriers
	15. Language/Cultural barriers



n=12 counties

CRS District 4 CYSHCN Profile, 2009-2010 (continued)

Service availability and burden ratings

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)
HEALTH SERVICES		
Dental	12 (100)	1.5
Developmental screening	12 (100)	2.0
Emergency care	11 (92)	1.2
Hearing/hearing aids	10 (83)	1.5
Mental health/behavioral	12 (100)	1.2
Nutrition	12 (100)	2.7
Occupational therapy	12 (100)	1.2
Physical therapy	12 (100)	1.2
Primary care	12 (100)	2.0
Special equipment or braces	10 (83)	1.2
Specialty care	10 (83)	1.2
Speech therapy	12 (100)	1.2
Vision/eyeglasses	12 (100)	1.7
COMMUNITY-BASED SERVICES		
Care coordination	12 (100)	2.0
Child care facilities/day care	11 (92)	1.3
Early Intervention	12 (100)	2.2
Education services	12 (100)	1.9
Family support	12 (100)	1.1
Planning for transition to adulthood	11 (92)	1.0
Recreation opportunities	12 (100)	1.1
Respite care	10 (83)	1.1
Summer/after-school care	10 (83)	1.1
Transportation assistance	12 (100)	1.2

*County provider survey, **Key informant interviews

Information needs identified by families

Family Survey; n=161

1. My child's condition or disability
2. Healthy behaviors (exercise, eating well, etc.) (tie)
Recreational activities (tie)
4. Successful persons living with condition/disability
5. Jobs/careers

Greatest service needs for CYSHCN and their families

Key informant interviews (# of counties indicating need)

- | | |
|---------------------------|-----------|
| 1. Transportation | 12 (100%) |
| 2. Therapies (OT, PT, SP) | 7 (58%) |
| 3. Specialty care | 6 (50%) |

CRS District 5, Montgomery CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 31,287¹
of Rural counties: 12 (86%)²
of Urban counties: 2 (14%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for District 5: 3.1

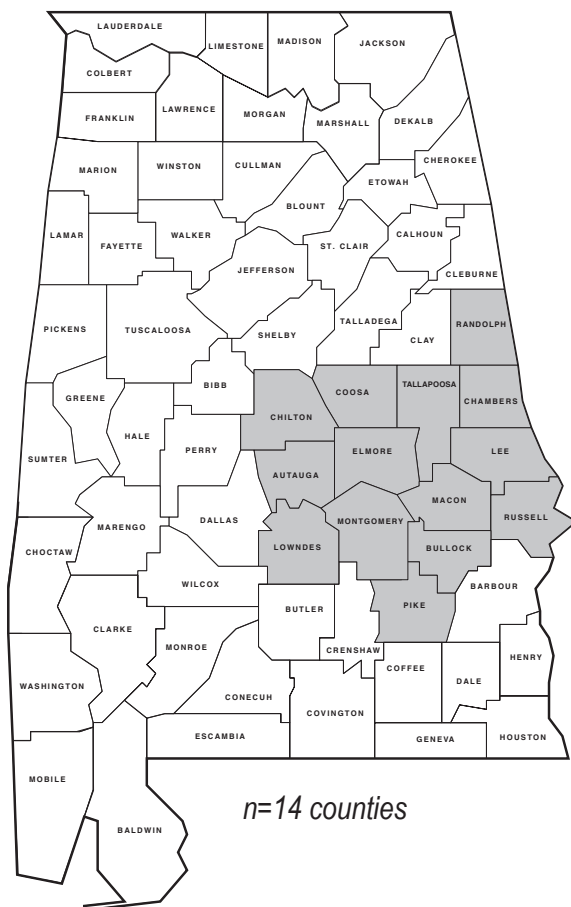
(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
(based on key informant interviews)

District at-a-glance

Mean % receiving SSI under age 18 ³	3.2
Mean % under age 18 living in poverty ⁴	27.9
Median income (\$) ⁵	34,510
Mean % under age 21 eligible for Medicaid ⁶	43.0
Mean % over age 25 with HS or greater education ⁷	69.7
Mean % over age 25 with BS degree or higher ⁷	14.9

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=114)
1. Transportation	1. Did not know where to go/who to see
2. Providers not available	2. Services too expensive
3. Lack of health insurance	3. Insurance didn't cover services
4. Families unsure how to use system	4. Providers not available (tie)
5. Lack of facilities with convenient locations (tie)	Hours/location of providers not convenient (tie)
Inadequate transition (tie)	6. Transportation
7. Lack of facilities with convenient hours	7. Can't afford co-pays and deductibles (tie)
8. Insurance does not adequately cover needed services (tie)	Waiting list for services too long (tie)
Lack of child care (tie)	9. Work conflict – Unable to take time off work
10. Lack of information on resources/health needs	10. Lack of child care
11. Cost of services too high	11. Work conflict – Can't afford to lose pay
12. Cultural/language barriers	12. Missed school days
13. State policy or administrative barriers	13. No insurance (tie)
	State policy or administrative barriers (tie)
	15. Language/Cultural barriers



n=14 counties

CRS District 5 CYSHCN Profile, 2009-2010 (continued)

Service availability and burden ratings

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)
HEALTH SERVICES		
Dental	13 (93)	2.2
Developmental screening	14 (100)	2.1
Emergency care	14 (100)	2.2
Hearing/hearing aids	14 (100)	2.0
Mental health/behavioral	13 (93)	1.5
Nutrition	14 (100)	1.5
Occupational therapy	14 (100)	2.0
Physical therapy	14 (100)	1.9
Primary care	14 (100)	2.4
Special equipment or braces	14 (100)	2.0
Specialty care	14 (100)	1.7
Speech therapy	14 (100)	2.2
Vision/eyeglasses	14 (100)	2.1
COMMUNITY-BASED SERVICES		
Care coordination	14 (100)	2.1
Child care facilities/day care	14 (100)	1.9
Early Intervention	14 (100)	2.1
Education services	14 (100)	2.4
Family support	14 (100)	1.7
Planning for transition to adulthood	14 (100)	1.5
Recreation opportunities	14 (100)	1.2
Respite care	13 (93)	1.1
Summer/after-school care	13 (93)	1.6
Transportation assistance	13 (93)	1.4

*County provider survey, **Key informant interviews

Information needs identified by families

Family Survey; n=114

1. Recreational activities
2. Successful persons living with condition/disability
3. My child's condition or disability
4. Jobs/careers
5. Healthy behaviors (exercise, eating well, etc.)

Greatest service needs for CYSHCN and their families

Key informant interviews (# of counties indicating need)

- | | |
|-----------------------------|----------|
| 1. Transportation | 11 (79%) |
| 2. Specialty care | 7 (50%) |
| 3. Mental health/behavioral | 6 (43%) |

CRS District 6, Dothan CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 14,942¹
of Rural counties: 9 (90%)²
of Urban counties: 1 (10%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for District 6: 3.5

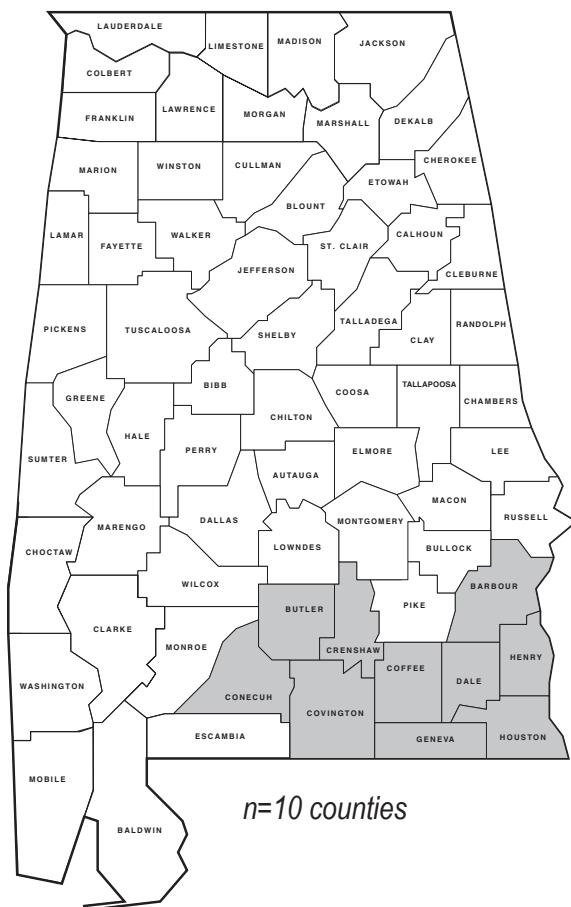
(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
(based on key informant interviews)

District at-a-glance

Mean % receiving SSI under age 18 ³	3.0
Mean % under age 18 living in poverty ⁴	29.1
Median income (\$) ⁵	33,445
Mean % under age 21 eligible for Medicaid ⁶	49.3
Mean % over age 25 with HS or greater education ⁷	68.8
Mean % over age 25 with BS degree or higher ⁷	12.8

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=113)
1. Transportation	1. Did not know where to go/who to see (tie)
2. Lack of child care	Transportation (tie)
3. Inadequate transition (tie)	Missed school days (tie)
Cultural/language barriers (tie)	4. Waiting list for services too long
Families unsure how to use system (tie)	5. Insurance didn't cover services
6. Insurance does not adequately cover needed services	6. Can't afford co-pays and deductibles
7. Cost of services too high	7. Providers not available (tie)
8. Lack of facilities with convenient hours	Work conflict – Can't afford to lose pay (tie)
9. Providers not available	9. Hours/location of providers not convenient
10. Lack of health insurance	10. Services too expensive (tie)
11. Lack of information on resources/health needs	Lack of child care (tie)
12. Lack of facilities with convenient locations	Work conflict – Unable to take time off work (tie)
13. State policy or administrative barriers	13. No insurance (tie)
	State policy or administrative barriers (tie)
	15. Language/Cultural barriers



n=10 counties

CRS District 6 CYSHCN Profile, 2009-2010 (continued)

Service availability and burden ratings

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)
HEALTH SERVICES		
Dental	10 (100)	1.9
Developmental screening	10 (100)	1.6
Emergency care	10 (100)	1.9
Hearing/hearing aids	10 (100)	1.8
Mental health/behavioral	10 (100)	1.5
Nutrition	10 (100)	1.5
Occupational therapy	9 (90)	1.4
Physical therapy	10 (100)	1.5
Primary care	10 (100)	2.4
Special equipment or braces	10 (100)	1.7
Specialty care	10 (100)	1.6
Speech therapy	10 (100)	1.2
Vision/eyeglasses	10 (100)	1.9
COMMUNITY-BASED SERVICES		
Care coordination	9 (90)	2.1
Child care facilities/day care	10 (100)	1.6
Early Intervention	10 (100)	1.9
Education services	10 (100)	2.0
Family support	10 (100)	1.6
Planning for transition to adulthood	9 (90)	1.3
Recreation opportunities	9 (90)	1.2
Respite care	8 (80)	1.0
Summer/after-school care	9 (90)	1.4
Transportation assistance	7 (70)	1.0

*County provider survey, **Key informant interviews

Information needs identified by families

Family Survey; n=113

1. My child's condition or disability
2. Successful persons living with condition/disability
3. Healthy behaviors (exercise, eating well, etc.)
4. Jobs/careers
5. How my child can take care of medical needs independently (tie)
How to find an adult caregiver when child reaches adulthood (tie)
Recreational activities (tie)

Greatest service needs for CYSHCN and their families

Key informant interviews (# of counties indicating need)

1. Transportation 10 (100%)
2. Child care (tie) 3 (30%)
After-school care (tie)
Specialty care (tie)
Therapies (OT, PT, SP) (tie)
3. Respite care 2 (20%)

CRS District 7, Mobile CYSHCN Profile, 2009-2010

Estimated Number CSHCN, 0-17 years: 30,150¹
 # of Rural counties: 6 (86%)²
 # of Urban counties: 1 (14%)²

How effective is the overall system of care in meeting the needs of CYSHCN and their families?

Average System of Care Rating for District 7: 3.7

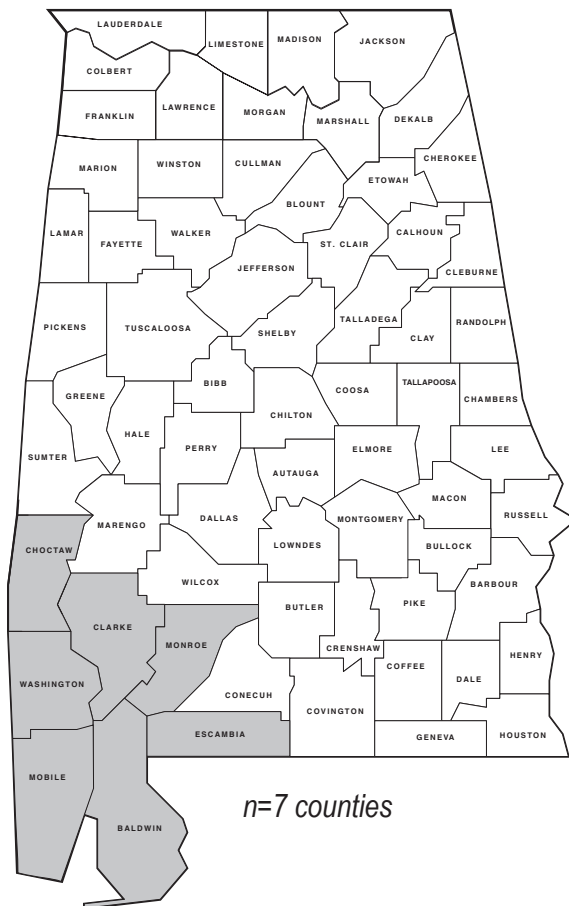
(1 = Excellent, 2 = Above average, 3 = Average, 4 = Below Average, 5 = Very Poor)
 (based on key informant interviews)

District at-a-glance

Mean % receiving SSI under age 18 ³	1.9
Mean % under age 18 living in poverty ⁴	28.0
Median income (\$) ⁵	34,615
Mean % under age 21 eligible for Medicaid ⁶	39.4
Mean % over age 25 with HS or greater education ⁷	71.9
Mean % over age 25 with BS degree or higher ⁷	13.5

Barriers to receiving services for CYSHCN and their families

County Provider Survey	Family Survey (n=98)
1. Transportation	1. Waiting list for services too long
2. Families unsure how to use system	2. Transportation (tie)
3. Inadequate transition	Work conflict – Can't afford to lose pay (tie)
4. Lack of child care	4. Insurance didn't cover services (tie)
5. Lack of facilities with convenient hours	Can't afford co-pays and deductibles (tie)
6. Lack of information on resources/health needs	Work conflict – Unable to take time off work (tie)
7. Insurance does not adequately cover needed services	7. Hours/location of providers not convenient (tie)
8. Providers not available (tie)	Did not know where to go/who to see (tie)
State policy or administrative barriers (tie)	Missed school days (tie)
10. Lack of health insurance (tie)	10. Lack of child care
Cultural/language barriers (tie)	11. Services too expensive
12. Lack of facilities with convenient locations	12. Providers not available (tie)
13. Cost of services too high	State policy or administrative barriers (tie)
	14. No insurance (tie)
	Language/Cultural barriers (tie)



n=7 counties

CRS District 7 CYSHCN Profile, 2009-2010 (continued)

Service availability and burden ratings

SERVICE	# of Counties Indicating Service Available in County or Adjoining County*	Average Rating of Burden to Obtain Service** (1 = Harder than expected, 2 = About what expected, 3 = Easier than expected)
HEALTH SERVICES		
Dental	7 (100)	1.6
Developmental screening	7 (100)	1.0
Emergency care	7 (100)	1.9
Hearing/hearing aids	5 (71)	1.3
Mental health/behavioral	7 (100)	1.0
Nutrition	7 (100)	1.0
Occupational therapy	6 (86)	1.1
Physical therapy	7 (100)	1.1
Primary care	7 (100)	2.4
Special equipment or braces	4 (57)	1.4
Specialty care	7 (100)	1.4
Speech therapy	6 (86)	1.0
Vision/eyeglasses	7 (100)	1.7
COMMUNITY-BASED SERVICES		
Care coordination	7 (100)	1.3
Child care facilities/day care	6 (86)	1.9
Early Intervention	7 (100)	2.4
Education services	7 (100)	2.4
Family support	5 (71)	1.3
Planning for transition to adulthood	6 (86)	1.0
Recreation opportunities	5 (71)	1.0
Respite care	6 (86)	1.0
Summer/after-school care	6 (86)	1.3
Transportation assistance	6 (86)	1.0

*County provider survey, **Key informant interviews

Information needs identified by families

Family Survey; n=98

1. Recreational activities
2. Successful persons living with condition/disability
3. Healthy behaviors (exercise, eating well, etc.)
4. My child's condition or disability (tie)
Jobs/careers (tie)

Greatest service needs for CYSHCN and their families

Key informant interviews (# of counties indicating need)

- | | |
|-----------------------------------|---------|
| 1. Transportation | 6 (86%) |
| 2. Mental health/behavioral (tie) | 5 (71%) |
| Therapies (OT, PT, SP) (tie) | |
| 3. Respite care | 2 (29%) |

SOURCES

DATA ELEMENT	SOURCE
1. <i>Estimated Number CSHCN 0-17 years</i>	Statewide estimate based on data from Child and Adolescent Health Measurement Initiative, 2005/2006 National Survey of Children with Special Health Care Needs, Data Resource Center for Child and Adolescent Health website. District estimates based on estimated percentage of Alabama population ages 0-17 years with special health care need from previous source (17.1%) multiplied by county estimates of Total Child Population 0-17 years from U.S. Department of Commerce, Bureau of the Census, Population Estimates Division, internet release date, June 9, 2010, special tabulation by the Alabama State Data Center, The University of Alabama.
2. <i># of Rural and Urban Counties</i>	What is Rural?, Alabama Rural Health Association, 2003
3. <i>Mean % receiving SSI under age 18</i>	Numerator from Social Security Administration, "SSI Recipients by State and County, 2008"; denominator from US. Dept. of Commerce, Bureau of Census, 2000, prepared by Alabama State Data Center at the University of Alabama.
4. <i>Mean % under age 18 living in poverty</i>	Percentage of children under age 18 years living below the federal poverty threshold, 2007, Small Area Income and Poverty Estimates, Bureau of Census.
5. <i>Median income (dollars)</i>	"County-level Unemployment and Median Household Income for Alabama," 2008, Bureau of Labor Statistics, Local Area Unemployment Statistics data, Bureau of Census, Small Area Income & Poverty Estimates Program, presented by U.S. Department of Agriculture, Economic Research Service.
6. <i>Mean % under age 21 eligible for Medicaid</i>	Percentage of total county population under age 21 years eligible for Alabama Medicaid, Alabama Medicaid Agency Statistics, FY 2007
7. <i>Mean % over age 25 with HS or greater education and mean % over age 25 with BS degree or higher</i>	"County-level Education Data for Alabama," 2000, Bureau of Census, presented by U.S. Department of Agriculture, Economic Research Service.

Primary Data Collection

County-Level Provider Survey, 2009

Family Survey (Families of Children and Youth with Special Health Care Needs), 2009

Key Informant Interviews, 2009

Youth Survey (Youth with Special Health Care Needs), 2009